Please select one answer per question.

Fatigue

1. Frequency

 ☐ 0 I *never or rarely* experience fatigue when I stand up

 ☐ 1 I *sometimes* experience fatigue when I stand up

 ☐ 2 I *often* experience fatigue when I stand up

 ☐ 3 I *usually* experience fatigue when I stand up

 ☐ 4 I *always* experience fatigue when I stand up

2. Severity

☐ 0 I *do not* experience fatigue when I stand up

☐ 1 I experience *mild* fatigue when I stand up

☐ 2 I experience *moderate* fatigue when I stand up and *sometimes* have to sit back down for relief

☐ 3 I experience *severe* fatigue when I stand up and *frequently* have to sit back down for relief

☐ 4 I experience *severe* fatigue when I stand up and *almost always* have to sit back down for relief

3. Conditions under which fatigue occurs

☐ 0 I *never or rarely* experience fatigue under any circumstances

☐ 1 I *sometimes* experience fatigue under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), or when exposed to heat (e.g., hot day, hot bath, hot shower)

☐ 2 I *often* experience fatigue under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), or when exposed to heat (e.g., hot day, hot bath, hot shower)

☐ 3 I *usually* experience fatigue under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), or when exposed to heat (e.g., hot day, hot bath, hot shower)

☐ 4 I *always* experience fatigue when I stand up; the specific conditions do not matter

4. Activities of daily living

☐ 0 Fatigue *does not interfere* with activities of daily living (e.g., school, work, chores, dressing, bathing)

☐ 1 Fatigue *mildly* interferes with activities of daily living (e.g., school, work, chores, dressing, bathing)

☐ 2 Fatigue *moderately* interferes with activities of daily living (e.g., school, work, chores, dressing, bathing)

☐ 3 Fatigue *severely* interferes with activities of daily living (e.g., school, work, chores, dressing, bathing)

☐ 4 *I am bed- or wheelchair-bound because of fatigue. (*Fatigue *severely* interferes with activities of daily living (e.g., school, work, chores, dressing, bathing}

5. Standing time

☐ 0 On most occasions, I can stand as long as necessary without experiencing any fatigue

 ☐ 1 On most occasions, I can stand *more than 15 minutes* before experiencing fatigue

 ☐ 2 On most occasions, I can stand *5-14 minutes* before experiencing fatigue

 ☐ 3 On most occasions, I can stand *1-4 minutes* before experiencing fatigue

 ☐ 4 On most occasions, I can stand *less than 1 minute* before experiencing fatigue

Lightheadedness

6. Frequency

 ☐ 0 I *never or rarely* experience lightheadedness when I stand up

 ☐ 1 I *sometimes* experience lightheadedness when I stand up

 ☐ 2 I *often* experience lightheadedness when I stand up

 ☐ 3 I *usually* experience lightheadedness when I stand up

 ☐ 4 I *always* experience lightheadedness when I stand up

7. Severity

☐ 0 I *do not* experience lightheadedness when I stand up

☐ 1 I experience *mild* lightheadedness when I stand up

☐ 2 I experience *moderate* lightheadedness when I stand up and *sometimes* have to sit back down for relief

☐ 3 I experience *severe* lightheadedness when I stand up and *frequently* have to sit back down for relief

☐ 4 I experience *severe* lightheadedness when I stand up and *regularly faint* if I do not sit back down

8. Conditions under which lightheadedness occurs

☐ 0 I *never or rarely* experience lightheadedness under any circumstances

☐ 1 I *sometimes* experience lightheadedness under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), when exposed to heat (e.g., hot day, hot bath, hot shower) or getting up too quickly from sitting or lying down

☐ 2 I *often* experience lightheadedness under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), when exposed to heat (e.g., hot day, hot bath, hot shower) or getting up too quickly from sitting or lying down

☐ 3 I *usually* experience lightheadedness under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), when exposed to heat (e.g., hot day, hot bath, hot shower) or getting up too quickly from sitting or lying down

☐ 4 I *always* experience lightheadedness when I stand up; the specific conditions do not matter

9. Activities of daily living

☐ 0 Lightheadedness *does not interfere* with activities of daily living (e.g., school, work, chores, dressing, bathing)

☐ 1 Lightheadedness *mildly* interferes with activities of daily living (e.g., school, work, chores, dressing, bathing)

☐ 2 Lightheadedness *moderately* interferes with activities of daily living (e.g., school, work, chores, dressing, bathing)

☐ 3 Lightheadedness *severely* interferes with activities of daily living (e.g., school, work, chores, dressing, bathing)

☐ 4 *I am bed- or wheelchair-bound because of lightheadedness.*

10. Standing time

 ☐ 0 On most occasions, I can stand as long as necessary without experiencing any lightheadedness

 ☐ 1 On most occasions, I can stand *more than 15 minutes* before experiencing lightheadedness

☐ 2 On most occasions, I can stand *5-14 minutes* before experiencing lightheadedness

 ☐ 3 On most occasions, I can stand *1-4 minutes* before experiencing lightheadedness

☐ 4 On most occasions, I can stand *less than 1 minute* before experiencing lightheadedness

Problems thinking and concentrating

11. Frequency

 ☐ 0 I *never or rarely* experience problems thinking and concentrating when I stand up

 ☐ 1 I *sometimes* experience problems thinking and concentrating when I stand up

 ☐ 2 I *often* experience problems thinking and concentrating when I stand up

 ☐ 3 I *usually* experience problems thinking and concentrating when I stand up

 ☐ 4 I *always* experience problems thinking and concentrating when I stand up

12. Severity

 ☐ 0 I *do not* experience problems thinking and concentrating when I stand up

 ☐ 1 I experience *mild* problems thinking and concentrating when I stand up

 ☐ 2 I experience *moderate* problems thinking and concentrating when I stand up and *sometimes* have to sit back down for relief

☐ 3 I experience *severe* problems thinking and concentrating when I stand up and *frequently* have to sit back down for relief

☐ 4 I experience *severe* problems thinking and concentrating when I stand up and *almost always* have to sit back down for relief

13. Conditions under which problems thinking and concentrating occurs

 ☐ 0 I *never or rarely* experience problems thinking and concentrating under any circumstances

☐ 1 I *sometimes* experience problems thinking and concentrating under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), or when exposed to heat (e.g., hot day, hot bath, hot shower)

☐ 2 I *often* experience problems thinking and concentrating under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), or when exposed to heat (e.g., hot day, hot bath, hot shower)

☐ 3 I *usually* experience problems thinking and concentrating under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), or when exposed to heat (e.g., hot day, hot bath, hot shower)

☐ 4 I *always* experience problems thinking and concentrating when I stand up; the specific conditions do not matter

14. Activities of daily living

 ☐ 0 Problems thinking and concentrating *do not interfere* with activities of daily living (e.g., school, work, chores, reading)

 ☐ 1 Problems thinking and concentrating *mildly* interfere with activities of daily living

 (e.g., school, work, chores, reading)

☐ 2 Problems thinking and concentrating *moderately* interfere with activities of daily living (e.g., school, work, chores, reading)

☐ 3 Problems thinking and concentrating *severely* interfere with activities of daily living (e.g., school, work, chores, reading)

☐ 4 Problems thinking and concentrating *always* interfere with activities of daily living (e.g., school, work, chores, reading)

15. Standing time

☐ 0 On most occasions, I can stand as long as necessary without experiencing any problems thinking and concentrating

☐ 1 On most occasions, I can stand *more than 15 minutes* before experiencing problems thinking and concentrating

☐ 2 On most occasions, I can stand *5-14 minutes* before experiencing problems thinking and concentrating

☐ 3 On most occasions, I can stand *1-4 minutes* before experiencing problems thinking and concentrating

☐ 4 On most occasions, I can stand *less than 1 minute* before experiencing problems thinking and concentrating

Blurry vision

16. Frequency

 ☐ 0 I *never or rarely* experience blurry vision when I stand up

 ☐ 1 I *sometimes* experience blurry vision when I stand up

 ☐ 2 I *often* experience blurry vision when I stand up

 ☐ 3 I *usually* experience blurry vision when I stand up

 ☐ 4 I *always* experience blurry vision when I stand up

17. Severity

 ☐ 0 I *do not* experience blurry vision when I stand up

 ☐ 1 I experience *mild* blurry vision when I stand up

☐ 2 I experience *moderate* blurry vision when I stand up and *sometimes* have to sit back down for relief

☐ 3 I experience *severe* blurry vision when I stand up and *frequently* have to sit back down for relief

☐ 4 I experience *severe* blurry vision when I stand up and *almost always* have to sit back down

18. Conditions under which blurry vision occurs

 ☐ 0 I *never or rarely* experience blurry vision under any circumstances

☐ 1 I *sometimes* experience blurry vision under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), or when exposed to heat (e.g., hot day, hot bath, hot shower)

☐ 2 I *often* experience blurry vision under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), or when exposed to heat (e.g., hot day, hot bath, hot shower)

☐ 3 I *usually* experience blurry vision under certain conditions, such as prolonged standing, after a meal, after exertion (e.g., walking), or when exposed to heat (e.g., hot day, hot bath, hot shower)

☐ 4 I *always* experience blurry vision when I stand up; the specific conditions do not matter

19. Activities of daily living

☐ 0 Blurry vision *does not interfere* with activities of daily living (e.g., school, work, chores, reading, dressing, bathing)

☐ 1 Blurry vision *mildly* interferes with activities of daily living (e.g., school, work, chores, reading, dressing, bathing)

☐ 2 Blurry vision *moderately* interferes with activities of daily living (e.g., school, work, chores, reading, dressing, bathing)

☐ 3 Blurry vision *severely* interferes with activities of daily living (e.g., school, work, chores, reading, dressing, bathing)

☐ 4 Blurry vision *always* interferes with activities of daily living (e.g., school, work, chores, reading)

20. Standing time

☐ 0 On most occasions, I can stand as long as necessary without experiencing any blurry vision

☐ 1 On most occasions, I can stand *more than 15 minutes* before experiencing blurry vision

 ☐ 2 On most occasions, I can stand *5-14 minutes* before experiencing blurry vision

 ☐ 3 On most occasions, I can stand *1-4 minutes* before experiencing blurry vision

☐ 4 On most occasions, I can stand *less than 1 minute* before experiencing blurry vision

## General Instructions

All elements on this CRF are considered Exploratory and should only be collected if the research team considers them appropriate for their study.

Please note that a parent form may be needed as an area of future improvement/development as some children may not be able to recall or understand questions that are being asked.

Note: This Exploratory CRF will require further question refinement as the ME/CFS CDEs are piloted.

Methodological questions that will need to be examined include:

* The lower age limit for comprehending the questionnaire.
* Agreement between parents and children on questionnaire items.
* Whether all 20 items are needed or whether a shorter questionnaire suffices.
* Whether further clarity on “when i stand” is needed (for example, do respondents need clarification on whether this refers to the act of standing up from a seated or recumbent position, or to the act of remaining standing, or both).

## Specific Instructions

Please see the Data Dictionary for definitions for each of the data elements included in this CRF Module.

Comment: The Orthostatic Grading Scale CRF is modified from the Orthostatic Grading Scale(Schrezenmaier et. al., 2005), which asks about "orthostatic symptoms". Because respondents with or without ME/CFS might not be familiar with what "orthostatic" symptoms are, the questionnaire has been expanded to ask about four common orthostatic symptoms (fatigue, lightheadedness, problems thinking and concentrating, and blurry vision).

References

1. Schrezenmaier C, Gehrking JA, Hines SM, Low PA, Benrud-Larson LM, Sandroni P. Evaluation of orthostatic hypotension: relationship of a new self-report instrument to laboratory-based measures. Mayo Clin Proc. 2005 Mar;80(3):330-4